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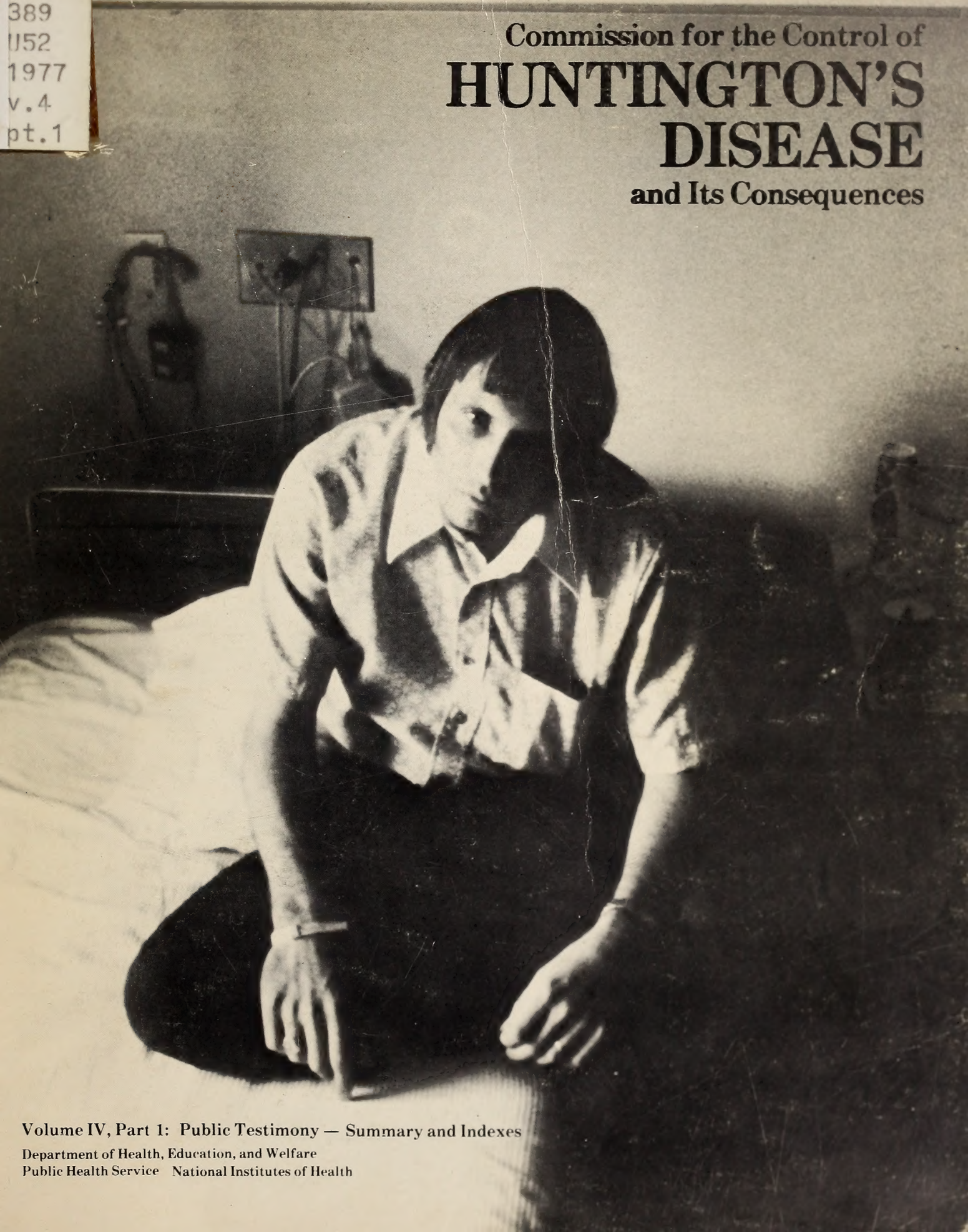
REPORT:

Commission for the Control of HUNTINGTON'S DISEASE and Its Consequences



Volume IV, Part 1: Public Testimony — Summary and Indexes

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REPORT:

United States Commission for the Control of

HUNTINGTON'S DISEASE

and Its Consequences

Volume IV, Part 1 — Public Testimony
Summary and Indexes

October, 1977

U.S. Department of Health, Education, and Welfare
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A geographic index of witnesses by hearing site is presented in each of the companion parts and immediately follows the chronological list of witnesses for each hearing site.

Summary

WHAT PEOPLE WERE TELLING THE COMMISSION

by
Maya Pines

Nearly two thousand persons testified or submitted written statements to the Commission for the Control of Huntington's Disease and Its Consequences. Most of them were desperate. As sons, daughters, wives, husbands or parents of Huntington's disease patients, they felt betrayed and abandoned by society.

They came from all walks of life, but some of these people were destitute because of the toll Huntington's disease had taken. Many lived in a state of constant and extreme anxiety. Some did not dare to give their names, for fear of discrimination by employers, insurance companies or neighbors.

In all the cities where the Commission held hearings--New York, Boston, Ann Arbor, Chicago, Atlanta, Seattle, Los Angeles, Denver, Dallas, Wichita and Washington, D.C.--the basic message was the same: There was nowhere to go for help. Not only did these people have to watch close relatives become abusive, violent, forgetful, unsteady, unable to work, and finally unable to walk, speak, or feed themselves; not only did they have to face the strong possibility of a similar fate for themselves or their children; but in addition they were almost totally deprived of support from any branch of society.

The doctors misdiagnosed the patients, misled their families, and often prescribed treatments that were actually harmful.

The insurance companies dropped them as soon as their disease was diagnosed--or even when they were at risk.

There were no homemakers or other helpers to assist in caring for the Huntington's disease patient at home or to take care of their children. There were no day care centers in the community to give them any respite or to allow the healthy member of the family to go to work.

The general hospitals turned them down. They could not afford nursing homes.

The mental hospitals to which the patients were usually shunted ignored them and sometimes let them starve or choke.

The social mechanisms which were supposed to help them financially, such as Social Security, Medicare, the Veterans' Administration, also failed them.

The patients' relatives had nowhere to go for counseling, to help preserve their own sanity in the midst of existing and impending disasters.

It was a nightmare, with no end in sight. The 370 physicians, researchers, therapists and other professionals who also testified or submitted written statements confirmed the near-total lack of services for the families of people afflicted with Huntington's disease. Together with the 1,337 non-professionals who told their stories, they painted a remarkably consistent picture of multiple need.

Overwhelmingly, the people who testified stressed the need for more research into the treatment and early detection of Huntington's disease, in the hope of some kind of prevention or cure--if not for themselves, at least for their children and for future generations. This was the largest single recommendation made. Eight hundred and twelve persons, nearly half of the total who testified, recommended more research.

Apart from research, the primary needs of Huntington's disease families that emerged from the testimony are as follows:

1. Facilities for Accurate Diagnosis. This was a recurrent theme. Over 200 persons reported that Huntington's disease patients in their families had been misdiagnosed (as having Parkinson's disease, or schizophrenia, or "nerves"). Frequently they were given L-dopa (which seriously aggravates Huntington's disease) or shock treatments, and some submitted to harmful operations. Meanwhile the family suffered from the patient's personality changes without knowing that they were caused by disease or realizing the hereditary nature of the disease--which led to numerous family break-ups and also deprived the family of the opportunity to make informed decisions about having children. A few examples from the testimony:

> My mother is now dying of Huntington's disease. She was declared mentally incompetent, as a paranoid schizophrenic, and was committed to the state hospital, where shock treatments were administered repeatedly. My beautiful mother never recovered from the great pain and suffering which resulted from this dreadful misdiagnosis. The disease has progressed until now she is completely helpless, weighing only 57 pounds, unable to talk or sit up, just lying there in a fetal position in her bed with only her eyes still alert.
>
> It wasn't until 1967 that mother's Huntington's disease diagnosis was confirmed, when we learned the hereditary implications of the disease. By that time, each of us, my brother, two sisters and myself, had married. We all had children...
>
> --Mrs. Jill Heesen
> Aurora, Colorado

In 1960 my wife entered Kirksville Osteopathic Hospital and Clinic and after complete examination and treatment, she ended up in Psychiatrics--with no diagnosis. In 1967 she entered St. Joseph's Hospital and Clinic at Centerville, Iowa. They could not find the cause of the trouble so they entered her in to the University of Missouri Medical Center at Columbia, Missouri. She went through seven clinical departments and after six months they did not diagnose the trouble.

In 1969 she entered Laughlin Hospital and Clinic for treatment of a fall and Dr. Valleck, a heart specialist, diagnosed the trouble as Huntington's chorea. What a relief! After hospitalization and seeing 31 doctors for services totalling over $36,000.00--one doctor recognized the disease.

--Donald Griffith
Chicago, Illinois

I have a 12-year-old son with Huntington's disease whose symptoms showed up in kindergarten but was not officially diagnosed until he was 10 years old. It has been a long, hard road with his problem in school, society and at home...My son was misdiagnosed, misplaced in schools, not accepted in society and we probably could have had a much better life if he was diagnosed earlier by doctors.

--Mrs. Dorothy Curtin
Baltimore, Maryland

I think this lack of doctors being able to recognize it is what is so desperate.

--Mrs. Nancy Hackler
Seattle, Washington

2. Need for help at home in the early stages of the disease, so that the patients do not fall and hurt themselves or accidentally set fire to the house.

The problem is the care of individuals who are beginning to show mental and behavioral deterioration...but are not yet so severely involved to require full hospitalization. They are a source of considerable depression to themselves and a cause of anxiety and emotional and financial burdens for their family and friends. Persons in this situation

truly fall through the cracks of our health care delivery system.

--Dr. Thomas Bird
Seattle, Washington

It wasn't skilled nursing I needed. I needed somebody to clean the house, some little things (to help me take care of my wife)...They would only allow it to be deducted if it had been a nurse. I couldn't afford a nurse and didn't need a nurse. What I needed was somebody to keep the house together...

--Dr. R. Sherwin Johnston
Chehalis, Washington

As the years went by, my mother had to stop driving and couldn't use stairs--she had several bad falls down stairs. And then she became somewhat demanding and insistent, and almost in a childlike way...I was flunking out of junior high school, as was my younger sister, and my father was beside himself with what to do.

--Mrs. Nancy House
McLean, Virginia

I am the wife of a victim of Huntington's disease... I watch him regress to a childlike being...As the sole support of the family, I must work...You go to work knowing you should be home looking after them, but you cannot. At work you always fear that a message will come of some accident.

--Mrs. Anna B. Sherwood
Baltimore, Maryland

3. Need for day care centers where Huntington's disease patients can spend some time under supervision and with therapists.

My husband is certainly not ready to be put into an institution. We do not want to put him in an institution. It is most important at this time, when he can still function, to keep him physically and mentally alert and active... We want him to be with us and we want to be with him. But how can you see this happen to a person and see them lay in bed from morning until night...and keep telling you that they're going crazy for the lack of something to do? And there's no place to take him and no facilities for him to

go to. If there were only places where he could go for the day. And come home and return to us at night and be with us. When they're put in institutions, nothing is done for them...

--Mrs. Florence Berger
New York, New York

4. Need for improved long term care--specialized nursing homes, not mental hospitals, for patients with more advanced Huntington's disease--places that families can afford.

The time came when my mother couldn't be cared for by my father any longer, and we tried to have her admitted to a nursing home nearby so that he could visit with her. Since we could not afford a nursing home for her, we applied for assistance. The only place the government agencies would allow her to go was a mental hospital!..She spent six months in the geriatrics ward of a mental institution, 105 miles away from her family and her home. Can you imagine what that did to all of us? Can you imagine what it did to a lady who has all her wits about her (better than I do) and is being punished because she can't walk by herself or feed herself or speak clearly? ...She often is black and blue from her elbows down to her hands because there are no beds with a protective padding for Huntington's disease patients. There is no special hospital equipment designed especially for the care of Huntington's disease patients such as wheelchairs that give head and neck support for eating and sitting up, or cups that don't spill liquids, or equipment designed for washing their hair...

--Jean Slade
Los Altos, California

In August 1976, I went door-to-door of nursing homes in the North Seattle area trying to find some place that would take a young man with Huntington's disease, partly on public assistance and social security. The search was frustrating and frightening. I did find a new, large home in Edmonds and Darrol is still there; but I received a call last week that they will not be able to keep him...This is a terrible feeling, not knowing of anywhere that will be willing to take care of him and see that he gets good care...

--Mrs. Frances Burhart Nielson
Woodinville, Washington

One of the greatest fears of all Huntington's disease victims is the fact that some day they will have to be put in a mental institution--and this is a constant fear of the Huntington's disease victims in my family.

--Marjorie C. Hoskins
Ellicott City, Maryland

5. The need for a place to get information on local resources and information about Huntington's disease itself. One hundred thirteen persons complained that even after the diagnosis of Huntington's disease was made they still had no access to adequate information about the disease. Doctors did not refer them to genetic counselors or to volunteer organizations which might have given them such information. And they had nowhere to go for guidance about how to cope with the social, financial and emotional aspects of living with the disease.

Most physicians in the community are not going to see an HD patient in their lifetime. I think the community education of the GP is...not the practical answer for most of them. The practical answer is to have the information well developed and well organized and to be able to readily and concisely transmit that information to those people that find they have a need for it, especially the developments regarding the therapy of the disease. The knowledge about the resources is just not adequately disseminated. There's no catalog in the library that I can go pick up that says Huntington's disease, and which lists the people in the area who have the experience and the agencies which will work with the disease.

--Dr. B. A. Rossin
Dallas, Texas

Suddenly my husband could not hold a job, became very selfish, self-centered, and changing jobs all the time. He didn't pay the bills, didn't care for nobody but himself. Why the changes, no one knew...He was admitted to the Harrisburg State Hospital for study. He became very ill and undernourished...I lost my home in Pennsylvania, my car for a mechanic's bill, and most of my furniture for a storage bill... In first grade my son began to show drastic changes; temper tantrums, kicking, and biting. We took him from one doctor to another. By now I had remarried and started a new life for myself and my children. The doctor said my son could not adapt to his new father, new environment. Others said he was spoiled. We doctored over seven years. My son kept getting worse...Finally they said Huntington's disease...They said we had to put him in a state hospital. I said no way.

For two years we tried Johns Hopkins, Georgetown, Children's, all of them; every hospital in our area; every drug, one after the other. We had appealed to our schools, churches, hospitals, the county, and the state. No one seemed to care.

Our son died April 1972, only three days after he was admitted to Hagerstown State Hospital, at the young age of 15. We were so broke, we had to borrow money for the funeral...We finally found out that all the time my son was qualified for Medicaid and not one single person had told us. Of course, by the time we found out, it was entirely too late because we had lost our son.

--Mrs. Darlene Slunt
Beltsville, Maryland

6. The need for genetic counseling and psychological support for members of the patient's immediate family. Five hundred seventeen persons testified about the psychological impact of Huntington's disease on the family--the trauma of learning about the presence of the disease, the difficulty of growing up in a household where a parent was afflicted with Huntington's disease, the mental and physical abuse inflicted by the Huntington's disease patient on his immediate relatives, and the stress of being at risk for the disease. Not surprisingly, many patients, spouses and at-risk persons turn to alcohol or drugs. Ninety-eight persons reported that Huntington's disease had led to divorce because the husband or wife could not endure being married to a Huntington's disease patient (sometimes they did not know that the bad behavior was caused by a disease). An equal number mentioned suicides and suicide attempts because of Huntington's disease. One hundred fifty-five persons discussed the special problems of those who are at risk.

When I talk of dying personalities, I'm also speaking of my own. When you live with a spouse that's afflicted with Huntington's disease long enough, you change too. You become irritable as you try to cope with all the problems that come along...Someone who cares for Huntington's disease people needs professional guidance too...We need someone who can counsel us, so we don't lose our own identities.

--Mrs. Hannah L. Geer
Los Angeles, California

When a person is developing a dementing disease, I think it's crucial that the family be worked with intensively to help them see the person not as becoming mean, irritable, nasty or depressed, but as really having this unfolding of personality changes that go with probably substantive brain, chemical and structural changes...Unless they can be helped to comprehend these changes, understand and accept them as part of something that's happening to the person, what you see is that the person gets rejected and the home disintegrates. As a consequence, the person loses the resources that are most important and most potentially stabilizing to him.

--Dr. B. A. Rossin
Dallas, Texas

Being at risk is never knowing. Even though I'm statistically young, when I get nervous about anything, or uptight, the tendency to think that it is Huntington's disease is awfully strong...I don't think I could ever emphasize the importance of some form of therapy to be made available to cover these particular areas...I want help to understand and to cope without messing up my life any more than it is. Someone to be able to reassure me that it's okay to get hazy-headed occasionally and to forget what you went to the cupboard for, without thinking Huntington's disease.

--Stella Runnels
Kingston, Washington

Of all the problems I have faced, perhaps the greatest was knowing that I could get Huntington's. As a teenager, I often thought that I'd kill myself before I'd let myself get like my brother Larry. When I was 20, I started imagining that I had it. When people would watch my hands, I'd get very nervous and I wouldn't be able to perform at all...It would have been a great help... if I had counseling.

--Carol A. Woods
Arlington, Texas

For many years, my father had been in and out of therapy and hospitalized twice for extreme depression. He also had shock treatment...The end result was a diagnosis of Huntington's disease...It took about two months for me to become so severely depressed that I ceased functioning almost completely. I simply couldn't live knowing all I knew about the disease, knowing tomorrow I might be

next, thinking the depression that had gripped me was telling me I had it already, thinking my daughter might get it (how do you tell your child?), thinking that since I was single and had hopes of someday remarrying, who would want me?

Last week my father refused to take his medication and then tried to kill my mother and himself. Today he is again in the hospital...It's terrible living with the guilt of wishing your father dead...I think the biggest problem was the fact that I had literally no one to turn to. I lived with my daughter alone. My brother couldn't accept the disease and I could not speak to him. My mother was not permitted to be made aware of it, so there was literally no one to talk to, and I was the one who was handling everything dealing with my father, since there was no one else, and I think that it was just too much for one person to attempt to handle. Unfortunately, there was absolutely nowhere to turn.

--Margaret Jones
New York, New York

7. The need for financial support and non-commercial insurance. Three hundred forty-one persons recommended to the Commission that in case of Huntington's disease, government financial assistance be mandatory. (This was the largest number to offer any single suggestion after the overwhelming demand for more research.) And financial worries permeated the testimony.

Financially, I was really getting destitute, because they weren't paying my mortgage, my phone bill was getting behind, my husband (a Huntington's disease patient) needed an operation, and quite frankly, I don't know how I lived through those years...After a year...they diagnosed my daughter as having Huntington's disease. She is 25 and that's been four years now...I was really in desperate need for help!

So I went to this social worker in my county, and I learned that in order for me to receive any help--I had five dependents--they told me that I made too much money; that I could only make $3,500 a year and have five dependents...This was 1974. $8,500 didn't do anything! Not when you have two people sick with Huntington's. But I wasn't entitled to any help, and I am still not entitled to any help.

--Mrs. Margaret Carruthers
Severna Park, Maryland

8. The need to educate physicians and nurses about Huntington's disease.

My daughter was born at Emory University in Atlanta--a very fine place. When I went to this obstetric group there, my mother-in-law was always in the back of my mind, and I said, my mother-in-law had Huntington's just recently. Oh well, that's all right, nothing to worry about! Each obstetrician that I had--God is my witness--I brought this up, and each one said, don't worry about that! Or I would never have had these children...The doctors need education; we need education.

--Mrs. Margaret Carruthers
Severna Park, Maryland

Most doctors I've come in contact with, I knew more about Huntington's disease than they did, even on the second visit when they'd had time to research it; which is very discouraging.

--Mrs. Nan Hackler
Seattle, Washington

Eventually she was referred to a "specialist" who made the Huntington's disease diagnosis. I will never forget his saying, "This disease is inherited but it only appears every third generation, so you and your brother and sister don't need to worry--by the time the third generation is here, they will have found a cure!" Never having heard of Huntington's disease, we did not question this statement...They say ignorance is bliss--we thought we were safe and Huntington's disease went out of our minds. In the ensuing years, my sister and brother and I had children of our own.

--Mrs. Marjorie C. Hoskins
Ellicott City, Maryland

I am a nurses' aide who has a patient with Huntington's disease, and I don't know how to take care of her. This patient can't be left alone when up in a wheelchair as she thrashes around so much, and she can't talk so I have no way of communicating with her...We need to learn more about this type of patient so we can take care of them.

--Marian M. Perkins
Fullerton, California

The psychiatrist herself knew nothing about the disease...The government can help by funding professional people to be trained to help those of us who are suffering with these kinds of neurological ailments...In terms of the general medical staff--nurses, doctors--these, too, need orientation in the field of what to do. They're all working in the dark. It's all been, from my experience, trial and error...Nobody knows how; what will work; what won't work. And even if they have found something that might help him, I don't know if the information is being passed on...The information, the kind of research, whether it's practical or medical, is not being filtered through the communications system at all.

--Mrs. Florence Siegel
New York, New York

The testimony is loud and clear in its description of what these people need. It is an urgent cry for help.

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n's Disease

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9701 Wilshire Blvd.
Beverly Hills, CA 90212
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